

Keynote Address
Presented to the Surgeon General's Conference on
Children With Handicaps and Their Families
At the Children's Hospital of Philadelphia
Philadelphia, PA
December 13, 1982

This lecture continued to be a foundation on which I built for the rest of my tenure as Surgeon General. First of all, it should be noted that a great many surgical patients that formerly died when they were operated upon as newborns had their lives saved, but also had traded, in a sense, death for a chronic illness requiring ventilator support on a respirator for weeks, months, and even years in the hospital. Dr. Allen Goldberg, a pediatrician and anesthesiologist, as well as an intensive care therapist, and a protégé of mine, pioneered with me in getting some of these children out of the hospital and into their homes, in spite of the fact that they were on a respirator. This started two new businesses. One that cared for ventilators and kept them in repair, and the other provided ancillary services, such as intravenous fluids, etc., for some of these patients tethered to a respirator.

But above all, it did return the child to the bosom of their family in his/her own community. This was of fundamental importance to events, which happened later surrounding the case of Katie Beckett. Katie Beckett was a child who later on was confined to a hospital in Iowa a number of miles from her family. She was covered for her hospital expenses by Medicaid, but that meant that she was thirty miles from her family, lacked their support and the environment of living at home, but in addition, she cost Medicaid about \$1500 a day for care on a respirator in the hospital in those days, whereas care at home on a respirator, could have been carried out for approximately \$800 per week.

Katie's mother, Julie happened to explain her concern about her child's absence from the center of the family to (her) Congressman Tauke, who told Vice President George Bush, who told President Reagan, who asked me to work the problem out. This led to the creation of something called the Katie Beckett waiver, which permitted children to leave the hospital on a respirator, and be cared for more comprehensively at home with far less expense to the government. There then came a Katie Beckett board of which I was the Chair and eventually, it guaranteed that every special needs child (including one on a respirator) was entitled to coordinated, comprehensive, family-centered, community-based care and that guarantee was included in Title V of the Social Security Act by Legislative Amendment.

The conference for which this lecture is the keynote was put together by the Department of Maternal and Child Health, especially Dr. Vince Hutchins, and Merle McPherson working with me on the general subject of handicapped children and their families. It was my contention that if a workshop were held on this particular subject, ventilator dependent children, – as difficult a one to move from hospital to home as one could imagine – it would serve as a template for any situation that came up, which presented the same dilemmas. It is also my first excursion into the realm of Surgeon General's conferences or workshops of which I held many during my tenure to introduce controversial issues and seek to set guidelines for the future. They were also held on such subjects as organ transplantations, self-help, drunk driving, and so on.

This is also my first return to the hospital where I had spent thirty-nine years as Surgeon-in-Chief while occupying the Chair of Pediatric Surgery at the University of Pennsylvania.

This conference dealt with many levels of complexity of the ventilator dependent child including the emotional, moral, the medical, the technological, the social, the psychological, and the financial.

I drew heavily on my experience as a pediatric surgeon in the institution where I was speaking, giving my own precepts on the care of patients and their families in the hospital setting and thereafter when the child was affected by a situation which was temporarily or permanently handicapping.

Communication with parents
Emotional complexity of subject
Financial complexity of subject
Full family participation in decision making
Infant mortality
Medical complexity of subject
Moral complexity of subject
Natural response of parents
Pediatric surgery
Psychological complexity of subject
Respirator dependent child
Cost
Longitudinal studies
Social services
Technology
Role of the family
Technological complexity of subject
Support groups for child & family